Treating the Physician

Research Thesis

Presented in partial fulfillment of the requirements for graduation *with research distinction* in

Comparative Studies in the undergraduate colleges of The Ohio State University

by

Kaitlyn Essig

The Ohio State University
May 2017

Project Advisor: Professor David Horn, Department of Comparative Studies

Treating the Physician

Kaitlyn Essig

The old gentleman sat down across from me. Graying hair, thin-wired bifocals, and a cup of espresso in his gentle hands. He spoke in a calm, quiet, but sure voice—carefully calculating his sentences so as not to waste any time. He used words that most of the time I didn't know, but his tone somewhat begged me to ask for an explanation. He loved to teach and he loved to learn, it was very clear. He always had a pen and a little black notebook sticking out of his shirt pocket to note anything of value, and carried a watch along his left hand. I always wondered about this gentleman, my grandfather, about the somewhat mystical life that he led. He lived and breathed medicine. He was a doctor, but it wasn't so much the title that defined him, but the life he lived as a doctor. For our family, he was the rock. We called him to consult on most medical questions before consulting our own doctors, we called him for our friends and for our neighbors. He was everybody's doctor. However, I began to wonder, who was his *doctor?*

It was a common scene to see me, a young college girl, sitting across from the old gentleman at restaurants around town, and often times these lunch meetings were interrupted by old patients or former students of my grandfather's wanting to thank him for doing his job. I remember one lunch sitting and listening to him teach me how important bedside manner is. He explained that most of his doctors were pretty relaxed—perhaps too relaxed—about his care and while it didn't bother him, he wanted to warn me to be careful (if I ever became a physician). He commented on how at a checkup where he was receiving a routine shot, his doctor had left the door to his room open while he went to retrieve the shot. This concerned him because here he was, an older gentleman, a former doctor, sitting without a shirt on, while

other patients and staff walked past him—thankfully, he said, none of those other patients was one of his own. At this point, I began to question, did my grandfather's title affect his treatment? What were some of the issues that his doctors had to consider when treating him?

It wasn't until a few months later, at another lunch meeting when he stopped me suddenly as we walked to our cars, that he began to explain: "Doctors think they are God. People think doctors are God. We can't save anyone's life; we can only prolong it." Looking back on that afternoon, I wondered if he knew more about what he was about to deal with in these next two years leading to his death than the rest of us. After all, he was the doctor. Was he beginning to realize he couldn't save himself?

A few months after this revelation he began to experience a decline in his health. When he told us of his undiagnosed health issues—fatigue, shortness of breath—he suggested that he had been experiencing these symptoms for a long time but put off a visit to his physician because he thought it was the demanding schedule of his job that was creating those issues. However, the symptoms continued after he retired and so he began to seek testing. He was first tested for heart issues, and at the time he thought he knew exactly what it was. He would write to me that it was possibly genetic, perhaps the family should all get tested. However, when those tests led to more tests he was clueless. He wasn't sure what his physicians were testing for at that point. While his cluelessness may have been a lack of confidence on his part, I wondered if he truly wasn't aware of what was going on with his care. After all, having been a patient myself, I had charted those unknown tests. Sure, he probably understood more than the average patient, but were his doctors leaving out information on the assumption that he knew? Or,

perhaps his doctors were treating him like an average patient, who was left without answers? Perhaps even the doctors didn't know: after all, they aren't God.

When it came time for his actual diagnosis, a rare form of bone marrow cancer, he began to explain it to me in a scientific way. He no longer had "cancer" in the way I've heard my friends and family describe "cancer"—as a tumor, getting sick, undergoing chemo—but rather an issue regarding proteins. His body was making proteins that were coating his cells. He knew exactly where and what was going on in his body. It was never a disease that was all of him, but rather a disease that was part of him. At one point he was told it was a "smoldering" disease, and he scoffed at such a non-scientific explanation. However, as time wore on, he too, resorted to metaphors, explaining that the medicines made him feel "feculent." It wasn't just his whole body that was sick, but his whole everything. And he knew it. He knew every tick on a list of what's to come. He was ready for it, but I believe he was ready for it in a way that the rest of us were not. He was a doctor, and he made medicine his life, but now he had no choice; his life depended on medicine.

As he grew sicker and sicker, he became an expert. He knew what kind of drug trials were around, what was worth trying and what wasn't. He was very independent throughout the beginning of his disease; he drove himself to the hospital for tests, and at one point even challenged his doctor after he had prescribed a drug that would limit his independence. He would up his oxygen on his own. He pretty much took care of himself, and in some regards I think he took pride in being a patient as he was finally able to experience what he had given to so many of his own patients—quality care. He proudly showed off his new walker, which he explained was a lot different than he thought. He then would tell me about his medicines, some

of which he had prescribed to his own patients, but for very different reasons. He found it comical that he gave his entire life to "prolonging lives," only to submit himself to his own colleagues, his own students, his own work. He was getting a go at what he spent his entire life taking care of: patients.

About two weeks before his death, he had fallen due to dehydration and found his way to the hospital. He didn't care for it much, as he had high expectations. His thoughts weren't as quick as they had once been and he spoke more slowly, in broken sentences, sometimes falling asleep in the middle of them and then waking back up. I watched as his role began to change from physician to patient. He demanded excellence from the entire hospital staff, as he knew things could be done more quickly—such as that ice cream he wanted. It started to show that he was never going back home, but he had managed to stay out of the hospital for the entire year he was sick. He was transferred to a hospice facility where he would receive comfort services for whatever time he had left.

I had been sitting next to his bed one morning, when his body temperature began to drop. He had been having chills, so I went to get him a blanket. On the warm spring day, he was covered with a hat, gloves, socks, and blankets upon blankets. He turned to me and said, "I don't know what to do." Someone in the room responded, that he didn't have to do anything, just relax, but there was a bit of panic in his voice. He knew he was dying. He knew his body temperature was going, and it wouldn't be long. He didn't know what to do. He didn't know how to be the patient on the other side. I told him I loved him, and with one big breath he turned to me and said, "I love you too." As the time grew nearer, his mind began to slip. With one hand he gripped the bedrails and with the other seemed to grasp at the air at something

the rest of us couldn't see. With one last breath, he was gone. He had finally experienced the one process medicine couldn't explain; it was life's big mystery. He was no longer the man in charge, but the man in the bed. They weren't treating just any patient; they were treating the physician.

The purpose of this research study is to explore some of the complexities present in treating and being a physician-patient. The study is informed by scholarly work on physician-patient dynamics, by a memoir written by a physician-patient, and by interviews I conducted with doctors at a Midwestern university hospital. By better understanding the challenges surrounding medical care for a physician-patient, the study hopes to provide a foundation for learning how to provide the best care for the physician-patient, and more generally to illuminate the dynamics of knowledge, power, and emotions that shape encounters between physicians and patients.

There is limited research in the United States regarding the medical care of physicians; however, there are a few studies that have been conducted in other countries with similar healthcare practices. Most scholarship regarding the physician-patient demonstrates the ambiguous status of the physician as patient, as well as the challenges physicians have in treating their peers and colleagues. One study of British physicians suggests that physicians are at risk for underestimating the seriousness of their illnesses and typically return to work sooner than they would advise their patients who are not physicians (Fox, Harris, Taylor, et. al.). Returning to work too soon is a safety risk for both physicians and their patients. Imagine having a physician who was mentally unstable, performing surgery on a patient—it could be

detrimental to both lives. Physicians may be unwilling to accept limits to their practice due to the realities of illness, citing work demands and their own education as the principal causes of their hesitation in seeking medical care.

The underlying expectations of a physician, based on his or her extensive medical knowledge, can impede the type of treatment a typical patient would receive. A study of junior physicians in Australia recognized that physicians are often left with few medical care options for reasons of their demanding work schedule or social pressure for physicians to be the ideal example of health (Markwell and Wainer). Those social pressures then lead to physicians self-treating. How do physicians access care? How does their work influence their abilities to do so? How do physicians become aware of this issue for their physician-patients? A different study of Australian physicians also found that 90% of the physicians who answered their survey on health-seeking behavior felt that self-treatment of acute conditions was acceptable (Davidson and Schattner). Not only is it easy to receive care using their own medical advice, but they are surrounded by other physicians who are also willing to write prescriptions without consultation. The same study also reported that general practitioners were less likely to receive care from another physician. For physicians who do seek medical treatment, there are often cases in which the boundaries that normally characterize the relationship between the physician and patient are blurred. Typical patients are often stripped of their social connection when they enter a physician's office. A physician may recognize their place of work, but not necessarily their performance in their jobs, their customers' satisfaction, nor would they typically know the kinds of social situations in which a patient lives. A typical patient is not often found to be connected to their physician outside of their appointments, whereas, physician-patients may

instead have their appointments with their physicians, then see them at an office gathering, and refer patients to one another, and then meet up Saturday evening for a night out on the town. When the typical physician and patient boundaries are crossed, it could become more difficult for the physician to be objective in the care of their friend/physician-patient.

A similar study in the U.S. recognized that in most cases physicians who are treating other physicians know them in both a professional setting and a social setting (Domeyer-Klenske and Rosenbaum). The inability to compartmentalize each relationship can lead to the physician-patient not seeking proper care, either out of fear or embarrassment about their illness, or due to their reluctance in revealing their private medical information to their colleagues. How do physician-patients choose their physicians? On what level do they know their physicians personally? How do relationships that extend beyond physician-patient boundaries influence the care given? The U.S. study also recognized that physicians often need to consider the comprehension level of the physician-patient's diagnosis and treatment (Domeyer-Klenske and Rosenbaum). While the field of general internal medicine (GIM) covers a wide range of specialties, primary care physicians (PCP) are not specialists in one particular area of the body. There is a general knowledge of the entire body. The issue in physician and physician-patient encounters is that when one specialist is seeking care from a specialist in another field, there are gaps in their shared knowledge. Most of the breakdown in communication comes from specific terms that are unique to each specialty, or that overlap but have completely different meanings. Based on these generalizations about physician-patient care, I developed interview questions to try to understand why physicians may or may not have

easier access to healthcare, how they seek healthcare, and the range of emotions they may feel regarding their care as a patient.

Relationships between physicians and patients generally have been a point of interest for both humanistic and sociological work, and the varied nature of those relationships have been identified as playing a key role in the care given to patients. While there are several ways to classify the roles of physician and patient, there is one particular model that helps to illuminate the physician and physician-patient model, specifically.

According to Gregory L. Weiss and Lynne E. Lonnquist's book, *The Sociology of Health, Healing, and Illness*, physicians Thomas Szasz and Marc Hollender developed a model that divides relations between physicians and patients into three types: activity-passivity, guidance-cooperation, and mutual participation. A physician and patient relationship that could be classified under the activity-passivity model is one that would reflect a physician who holds the power, the education, the expertise to make all the best decisions regarding the patient (Weiss and Lonnquist 274). Activity-passivity relationships are compared to a relationship between a parent and young child, the patient being a young child and the doctor being the parent (274). The patient trusts the physician to use those tools to make the best decisions regarding their care, without need of challenging from the patient and little explanation to the patient in regards to why a particular treatment was chosen. The guidance-cooperation model would be considered the ideal model for a typical physician-patient encounter (274). In this relationship type, it is assumed that the patient has some autonomy: the ability to express pain, emotion, fear, and to have concerns regarding their care and treatment. In these encounters, the patient is like a teen while the physician is like a parent. The physician still remains the decision maker,

but there is a larger dialogue that is not present in the activity-passivity model, and that allows for more freedom of the patient to have a say. However, the mutual participation model best explains the relationships between the physician and physician-patient. Weiss and Lonnquist describe it as follows:

> Based on a view that equalitarian relationships are to be preferred in medicine, this model elevates the patient to full participant. In this case, both physician and patient acknowledge that the patient must be a central player for the medical encounter to be successful. The patient knows more about her or his own situation—medical history, symptoms, and other relevant events—than does the physician. While the physician attempts to ask the proper questions to elicit key information, it is assumed that the patient also has an obligation to ensure that relevant information is disclosed (Weiss and Lonnquist 274).

As is typically the case in the physician and physician-patient relationship, they argue, both parties in "mutual participation" have equal amounts of power and authority. Regardless of the equal-power dynamic that is present in the relationship, it is assumed that the physician needs the physician-patient in order to successfully maintain a relationship, and the physician-patient needs the physician in order to maintain health—a physician expects the patient will provide a dialogue assuming they will step in where needed, while the patient expects that the physician will take their information and provide a diagnosis and treatment. Both parties rely on each other in order to be successful in their roles as either physician or patient. When presenting information, a physician-patient may be more likely to present pertinent information to the physician who is also posing routine questions. However, Weiss and Lonnquist explain that the relationships that develop between a physician and patient are determined and developed by the orientation of power: "…physicians have the potential to command the decisive voice. But many physicians now reject this position, and many patients have been socialized not to let them assume it" (Weiss and Lonnquist 275). The mutual participation model is not limited to

physicians and their physician-patients; in fact, it is often the preferred model for people who are well-educated and have above average health seeking behaviors. Not surprisingly, this model is often not available to those found in marginalized or disempowered groups.

The ability for the patient to make decisions has become an important component of the physician and patient relationship. In some cases, a patient may be limited in their abilities to make educated decisions, and not only because of a lower education background—gender, race and socioeconomic status may also play a role in how a patient exercises autonomy. However, most physician-patients would have the necessary educational background to maintain autonomy in their healthcare decisions, regardless of social constructions.

Having autonomy in the case of a physician and patient relationship is where the physician and patient are able to recognize that the patient has the capability to decide for themselves what plan of care is best. However, in order for the patient to gain autonomy the physician must grant respect for their abilities to do so (Weiss and Lonnquist 277-6). In other words, the physician must see their patient as educated enough—and perhaps in some cases, wealthy enough, successful enough and empowered enough—to take care of themselves, to make educated decisions. In contrast to autonomy, beneficence in the physician and patient relationship is the role of the physician to do what is best for the patient. In order for beneficence to play a role in the relationship, the patient must be deemed unable to make decisions that are beneficial in their care and the physician must decide what is in the best interest of the patient (Weiss and Lonnquist 278). The physician and physician-patient relationship may see a combination of the two. In some cases, the physician respects the physician-patient's background and education and may agree with their self-diagnosis, their

concerns, and the suggestions of certain tests and plans of care. However, in some instances the background and education of a physician-patient may inhibit their abilities to remain objective in their own care, thus causing the physician to rely on beneficence as a determining factor in their diagnosis, concerns, tests, and plans of care. The balance between autonomy and beneficence is difficult to achieve in the care of a physician-patient, as represented through the story of a famous writer and physician-patient, Paul Kalanithi.

Paul Kalanithi wrote about his experiences of being a physician and a patient in his book, *When Breath Becomes Air*. As a neurosurgical resident, he was training to perform life and death operations where a millimeter of mistake could cost someone their life. However, in the midst of practicing he grew sick. Back pain crippled him as his marriage to his wife, Lucy, an internal medicine physician, started to fall apart. After long and arduous visits to his physicians, he was eventually diagnosed with cancer. He writes about his difficulty in separating his role of being a physician and being a patient throughout the book—the struggle between owning his autonomy and respecting his physician's beneficence. In an attempt to diagnose his crippling back pain, he expressed how conflicted he felt in respecting his own physician's orders. The beginning of the memoir best reflects this difficult feat of a physician-patient in diagnosis. It begins,

> I FLIPPED THROUGH THE CT scan images, the diagnosis obvious: the lungs were matted with innumerable tumors, the spine deformed, a full lobe of the liver obliterated. Cancer, widely disseminated. I was a neurosurgical resident entering my final year of training. Over the last six years, I'd examined scores of such scans, on the off chance that some procedure might benefit the patient. But this scan was different: it was my own.
>
> I wasn't in the radiology suite, wearing my scrubs and white coat. I was dressed in a patient's gown, tethered to an IV pole, using the computer the nurse had left in my hospital room, with my wife, Lucy, an internist, at my side. I went through each sequence again: the lung window, the bone window, the liver

window, scrolling from top to bottom, then left to right, then front to back, just as I had been trained to do, as if I might find something that would change the diagnosis.

We lay together on the hospital bed.

Lucy, quietly, as if reading from a script: “Do you think there’s any possibility that it’s something else?”

“No,” I said.

We held each other tightly, like young lovers. In the past year we’d both suspected, but refused to believe, or even discuss, that a cancer was growing inside me.

About six months before, I had started losing weight and having ferocious back pain. When I dressed in the morning, my belt cinched one, then two notches tighter. I went to see my primary care doctor, an old classmate from Stanford. Her sister had died suddenly as a neurosurgery intern, after contracting a virulent infection, and so she’d taken a maternal watch on my health. When I arrived, however, I found a different doctor in her office—my classmate was on maternity leave.

Dressed in a thin blue gown on a cold examining table, I described the symptoms to her. “Of course,” I said, “if this were a boards exam question—thirty-five-year-old with unexplained weight loss and new-onset back pain—the obvious answer would be (C) cancer. But maybe it’s just that I’m working too hard. I don’t know. I’d like to get an MRI to be sure.”

“I think we should get X-rays first,” she said. MRIs for back pain are expensive, and unnecessary imaging had lately become a major national point of cost-saving emphasis. But the value of a scan also depends on what you are looking for: X-rays are largely useless for cancer. Still, for many docs, ordering an MRI at this early stage is apostasy. She continued: “X-rays aren’t perfectly sensitive, but it makes sense to start there.”

“How about we get flexion-extension X-rays, then—maybe the more realistic diagnosis here is isthmic spondylolisthesis?”

From the reflection in the wall mirror, I could see her googling it.

“It’s a pars fracture affecting up to five percent of people and a frequent cause of back pain in the young.”

“Okay, I’ll order them, then.”

“Thanks,” I said.

Why was I so authoritative in a surgeon’s coat but so meek in a patient's gown? The truth was, I knew more about back pain than she did—half of my training as a neurosurgeon had involved disorders of the spine. But maybe a spondy was more likely. It did affect a significant percent of young adults—and cancer in the spine in your thirties? The odds of that couldn’t be more than one in ten thousand. Even if it were one hundred times more common than that, it’d still be less common than a spondy. Maybe I was just freaking myself out (Kalanithi 3-6).

At this point, the readers begin to recognize that Kalanithi struggled in being both the physician and the patient. The order in which he writes this introduction portrays the countering opinion that he in fact is sure it is cancer, but that in the moment of facing such a diagnosis, he was not so confident. His education produced a bias in his thoughts, his mind instantly went to the worst possible case, as he had seen before. He was his own case. He tried to obtain autonomy in his diagnosis, refuting his own physician and questioning if she knew all that he knew. Instead, his physician recognized his bias, his personal experiences as a physician-patient and treated him as though he was an average patient who would have been unaware of the future possibilities of disease. His physician became beneficent, taking away Kalanithi's autonomy. How did this hurt him? He ended up dealing with the pain, only to come to a conclusion in his own mind that it was indeed cancer, later to be confirmed by his physician. He knew deep down it was cancer, but his own physicians did not. His own denial and self-doubt of his medical diagnosing capabilities led him to lose empowerment and confidence in his care as a patient. However, facing these vulnerabilities as not only a patient but a physician creates complicated responses to illness and diagnosis alike. In this case, there are issues with the physician and physician-patient relationship. At what point should the physician respect the autonomy of the physician-patient, and at what point is it a good idea to recognize possible biases of the physician-patient and become beneficent?

By the time he was diagnosed with cancer, Kalanithi had been connected to a new physician and oncologist, Dr. Emma Hayward. Throughout the story, Dr. Hayward continually had to keep Kalanithi as a patient and a patient only. He was no longer a physician. He writes about his first encounter with Dr. Hayward,

> "Hi, my name is Emma," she said. "I'm sorry to have to be so brief today, but I wanted to come by and introduce myself."
>
> We shook hands, my arm entangled in the IV line.
>
> "Thanks for stopping by," I said. "I know you have kids to pick up. This is my family." She nodded hello at Lucy, at my brothers and parents.
>
> "I'm sorry this is happening to you," she said. "To all of you. There will be a lot of time to talk in a couple days. I went ahead and had the lab start running some tests on your tumor sample, which will help guide therapy. Treatment may be chemotherapy or not, depending on the tests."
>
> Eighteen months earlier, I'd been in the hospital with appendicitis. Then I'd been treated not as a patient but as a colleague, almost like a consultant on my own case. I expected the same here. "I know now's not the time," I proceeded, "but I will want to talk about the Kaplan-Meier survival curves."
>
> "No," she said. "Absolutely not."
>
> A brief silence. *How dare she?* I thought. *This is how doctors—doctors like me—understand prognostication. I have a right to know.*
>
> "We can talk about therapies later," she said. "We can talk about your going back to work, too, if that's what you'd like to do. The traditional chemotherapy combination—cisplatin, pemetrexed, possibly with Avastin, too—has a high rate of peripheral neuropathy, so we'd probably switch the cisplatin for carboplatin, which will protect your nerves better, since you're a surgeon."
>
> *Go back to work? What is she talking about? Is she delusional? Or am I dead wrong about my prognosis? And how can we talk about any of this without a realistic estimate of survival?* The ground, having already buckled and roiled over the past few days, did so again (Kalanithi 122-3).

Kalanithi at this point in the book becomes stripped of his power as a physician—his ability to know, to predict, and understand—as it is in perhaps his best interest that he doesn't know his odds of survival. At the same time, his physician wants to consider what was in the best interest of her patient. She still offered him respect as a physician by using medical terminology to explain his treatment plans. As his care plan went forward, he talks about his encounter with Dr. Hayward,

> The next day, a Saturday, Emma called. I asked her what she thought about chemotherapy agents.
>
> "Well," she said. "Do you have specific thoughts?"
>
> "I guess the main question is whether to include Avastin," I said. "I know the data is mixed and that it adds potential side effects, and some cancer centers are turning away from it. In my mind, though, since there are a lot of studies

> supporting its use, I'd lean toward including it. We can discontinue it if I have a bad reaction to it. If that seems sensible to you."
>
> "Yeah, that sounds about right. Insurance companies also make it hard to add it later, so that's another reason to use it up front."
>
> "Thanks for calling. I'll let you get back to enjoying the lake."
>
> "Okay. But there's one thing." She paused. "I'm totally happy for us to make your medical plan together; obviously, you're a doctor, you know what you're talking about, and it's your life. But if you ever want me to just be the doctor, I'm happy to do that, too."
>
> I hadn't ever considered that I could release myself from the responsibility of my own medical care. I'd just assumed all patients became experts at their own diseases. I remembered how, as a green medical student, knowing nothing, I would often end up asking patients to explain their diseases and treatments to me, their blue toes and pink pills. But as a doctor, I never expected patients to make decisions alone; I bore responsibility for the patient. And I realized I was trying to do the same thing now, my doctor-self remaining responsible for my patient-self. Maybe I'd been cursed by a Greek god, but abdicating control seemed irresponsible, if not impossible (Kalanithi 181-3).

As represented in this excerpt, it isn't an easy feat for physicians to forget years of training and to allow others to use their training to treat them. Physicians spend years learning to think critically in such cases, to weigh the benefits and risks associated with treatments for such an illness; so much so, that it becomes natural to be involved in the process as a patient. However, the biases of the physician-patient can limit the treatment and in some cases even the outcomes of the illness and diseases, as we see in Kalanithi's experiences. Kalanithi's own physician wanted to disregard his original diagnosis of cancer, attempting not to be swayed by his self-diagnosis and attempting to remain objective—however, at what point does that become an issue? The simple suggestion that perhaps it might be cancer was enough for not only his doctor, but also for Kalanithi, to back away from such a daunting diagnosis. While ultimately it is the physician who decides on a plan of care, those physicians may be more willing to listen to the requests of a physician-patient due to their background in medicine, or not, in the case of Kalanithi. The access to information and to the physician themselves can also

benefit their care, as we saw with Kalanithi's first experience of the illness: if his physician had listened to him instead of following typical patient protocols, he might have been diagnosed sooner and treated sooner. However, it is the complexities that a physician-patient adds to the mutual participation model that makes the physician and physician-patient relationship a difficult one to characterize.

Perhaps it is not until a physician experiences life as a patient with a serious illness, one who is dependent on hospital care and treatment, that they begin to realize the complexities of the subjective experience of being a patient. Kalanithi writes,

> I had sent nearly every one of my patients to physical therapy. And now I found myself shocked at how difficult it was. As a doctor, you have a sense of what it's like to be sick, but until you've gone through it yourself, you don't really know. It's like falling in love or having a kid. You don't appreciate the mounds of paperwork that come along with it, or the little things. When you get an IV placed, for example, you can actually taste the salt when they start infusing it. They tell me that this happens to everybody, but even after eleven years in medicine, I had never known (Kalanithi 140).

Kalanithi admits, that as a physician, until you truly experience what your patients are going through, it is impossible for you to understand the feeling of illness. The realization that physicians too experience illness, infection, and injury, and that there is no amount of medical knowledge that can prevent physicians from succumbing to the laws of human living, is transformative. With the new understanding, that medicine has a subjective dimension, Kalanithi writes,

> While being trained as a physician and scientist had helped me process the data and accept the limits of what that data could reveal about my prognosis, it didn't help me as a patient. It didn't tell Lucy and me whether we should go ahead and have a child, or what it meant to nurture a new life while mine faded. Nor did it tell me whether to fight for my career, to reclaim the ambitions I had single-mindedly pursued for so long, but without the surety of the time to complete them.

> Like my own patients, I had to face my mortality and try to understand what made my life worth living—and I needed Emma's help to do so. Torn between being a doctor and being a patient, delving into medical science and turning back to literature for answers, I struggled, while facing my own death, to rebuild my old life—or perhaps find a new one (Kalanithi 139).

The realization by Kalanithi, that there was no amount of medical education that could keep him from the inevitable, became a sobering moment. These comments often reminded me of those of my grandfather, his admittance that in the midst of dying he didn't know what to do. He, along with Kalanithi, was no longer in charge. Both patients came to rely on their physicians to make these human decisions, as to whether life was still worth living and to what extent my grandfather and Kalanithi could live it. With the removal of responsibility from the physician-patients as being in control of their own care, they submit themselves instead to a lack of protection for themselves, but also to vulnerability and a reliance on their physicians, their families, and their friends. The realization that physicians are not robots, that they must be human outside of disease, is a realization that perhaps only the physician-patients themselves would recognize if only they were faced with the very fragility of life. For it is in this recognition, the inevitability that with life comes death, that the physician is no longer the physician in the scenario, but the patient. Wholly and exclusively, the man in the bed.

Physicians are human, just like the rest of us; they get sick and they get hurt. However, after interviewing five physicians it is clear that the experience and standard of care they receive is different from the typical patient. First, of the physician-patients who were interviewed, there are suggestions that physician-patients have similar primary care seeking behavior as the typical patient; they ask their friends and colleagues. However, for physicians

their friends and colleagues are some of the best, most recommended physicians for their needs. Those connections oftentimes allow for physician-patients to get seen more quickly. For most physician-patients, they see a physician within their practice network. Oftentimes this means that the physician-patient is, at the very least, aware of their physician in a work-type setting and in some cases a social setting. A few physicians indicated that their physician-patients sought them out through colleagues who had known the physician before. In these cases, where the physician-patients and physicians work in a close network, physicians must work carefully to distinguish the visits between colleague-connection and patient-connection. One interview subject said the following about seeing other physicians:

> *Ultimately, I'm perfectly happy to see another physician, but it did take a fair amount of thought to kind of go, al lright, who do I want to see? How well connected do I want to be with them? So I purposefully picked someone that I know of but didn't really, really know* (Interview 4T1).

However, one must ask the question, what changes when the typical physician-patient boundaries are crossed, especially in the case of physician-patients who may struggle to find a physician outside of their social circle but within their insurance network?

In addition to having access to a large network of recommended caregivers, physician-patients also tend to have easier access to their physicians, contrary to the research study published by Markwell and Wainer. Some interview participants indicated that they would make time for their physician-patients, even during a full day or when they are no longer accepting new patients, by taking them during their lunch hour. Not only were physician-patients given easier access to scheduling, according to research interviews, but they were also given easier access to their physicians. A few physicians described freely providing their cell

phones and email addresses, noting that while very few of their physician-patients took advantage of this access, they felt that the schedule of the physician-patient warranted the direct contact. Then, stating that as a physician it is annoying to cancel on their patients and reschedule into a later schedule which may already be determined, in order for the physician to make time to see their own physicians. When asked how physician-patient's needs were similar or different from typical patients, one physician replied,

> *Similar is the generic health maintenance and just because you are a physician doesn't mean you don't need to have a pap smear or mammogram or blood work, things like that. I think we are different in that typically we minimize symptoms and don't necessarily reach out for the care that we need. Therefore, things get pushed to the wayside or we don't have time to necessarily to get in and go to the doctor. So, I'll get more text messages or phone calls or messages and things like that from people because it's like, I can't come in for a visit but—I think in general we are pretty bad about reading our own symptoms and that probably goes into the minimizing piece of things as well. Sometimes we know too much for our own good* (Interview 3A2).

For the interviewed physicians providing care for physician-patients, the approach to appointments is the same regardless of who is waiting inside the room—whether it be a physician or a non-physician. One physician interviewed said,

> *I don't think I approach it much differently than anybody else, as far as the actual appointment. In general, with my visits, it is kind of an open 'what do you need me for?', 'Is there anything I need to pick on you about?' For example, my uncontrolled diabetic: 'Okay, what do you need from me? Okay, your hip hurts, we'll talk about that, but your A1C is 8.6. I need to talk to you about the fact that your diabetes is not controlled.' I would say, with physicians, I probe sometimes a little bit more. We talk a little bit more about how things are going at work, kind of try to support them with stressors and things like that and try to boost them up a little bit, but other than that, I think they are fairly similar* (Interview 3A2).

All five physicians who were interviewed answered with a similar response to the above question, suggesting that there were no extra preparations made prior to physician-patient

appointments. Office time spent with physician-patients was reportedly the same as with non-physician patients; however, as the interview from above (Interview 3A2) suggests, that time may be spent *differently* with physician-patients. Many physicians who were interviewed felt they spent some time during their physician-patient appointments discussing work politics and providing emotional support in the form of camaraderie for shared medical experiences. There is a certain sense of "friendship" that comes from the discussion of politics and providing a pep talk to their physician-patients. This suggests that the physician community shares concerns of work burn out, as well as fear of failure in their job, and that the pressures of work are important enough to be addressed during physician-patient appointments.

When it comes time for the patient to present their symptoms/illness to their physicians, physician-patients present differently than non-physician patients. One physician suggested that physician-patients present in a way that is more direct by saying,

> *They [physician-patients] provide the information in a very easy to process way because they are used to collecting that information. And so, generally, it's a pretty straightforward interaction but certainly sometimes the way we [physicians] communicate is different than other patients because I can talk in the lingo* (Interview 4T1).

Regardless of their abilities to present illness, perhaps the most fascinating finding from these interviews was that physician-patients have a tendency to present their symptoms in a way that could possibly create a misrepresentation of their actual condition. The reason is that physician-patients are fully aware of illness scripts (Interview 5E4). Illness scripts are the characteristic summaries of a disease that allow physicians to categorize descriptions of disease into pathology, epidemiology, symptoms/signs, tests, and treatment options (Geha, Connor and Kohlwes et. al.). For example, imagine that a non-physician patient presents to their physician

with a sore throat. When the non-physician patient reports to their physician, the typical dialogue would consist of the physician asking questions that would help sift through their illness scripts in order to provide a diagnosis. The physician might ask something along these lines: How long has this been going on? Do you have any coughing or drainage? Have you had fever or chills? Does it hurt to swallow? Is your throat scratchy? Have you been to a concert or sporting event recently that you would've been using your voice excessively? Have you noticed any spots on the back of your throat? Eventually, the physician would rule out possible diagnoses and hopefully settle on one that is useful to the patient.

However, when physician-patients present their symptoms they may do so differently. For example, imagine a physician-patient presents to their physician with a sore throat. When the physician-patient reports to their doctor, the typical dialogue may consist of something along the lines of: I have had a sore throat for x number of days, there are no spots on the back of my throat, but I have had a low-grade fever. I've been taking x medication. I haven't had to use my voice excessively, so I think it must be tonsillitis, what do you think? Thus, the physician-patient has used their own illness scripts to come to the conclusion of a self-diagnosis, or to at least present their symptoms in a way for their treating physicians to understand what their physician-patients think it could be, whether this is directly or indirectly stated. Some physicians noted that if a physician-patient contacted them and explained their symptoms over the phone, they could prescribe over the phone. (However, most of those physicians indicated that they would do the same for an average patient.)

Of the interviewed physicians, a few suggested that they receive different care from physicians when seeking care. When commenting on their special treatment s/he had received during a hospital visit, one physician said,

> *I tried not to let the staff know that I was a physician because they definitely treat you differently and I don't want to be different. I don't need better or worse, I just want what everybody else is getting. Yeah, so that's always tricky* (Interview 1H3).

The interviewed physicians commented that their special care often came in the form of their physicians' staying after their shifts had ended in order to see them through their medical procedures. One physician suggested that there were differences even in the care of family members; their status had both pros and cons as they were able to be present during different tests to which family members are typically not privy (Interview 2R5 and Interview 3A2). Perhaps the bigger question in regards to receiving "special treatment" is whether or not it is always something that physician-patients want or need. In one instance, a physician who was interviewed said this about treating physician-patients who come in with a self-diagnosis:

> *I don't know if I do the best job of personally challenging that. Unless it is really out there. So that is something that does concern me, if I'm taking care of physician-patients. As far as, do I end up doing more imaging, more work up, things like that? Probably, because I have a hard time, probably, with self-confidence of telling them that they are wrong* (Interview 3A2).

The dynamics of power and knowledge that are present in physician-patient visits also shape the tone with which the appointments are handled. The treating physician may be concerned not only to show deference to education of their physician-patients, but also to avoid mistakes and criticism—after all, physician-patients are also experts in the same medical field, and may know when things are handled properly or not. One physician commented on these concerns by saying,

> I think they [physician-patients] vary, just in terms as the rest of the population. Most of the physicians I take care of are—I try not to take a different approach to their care. I think one of the things is—I know I'm sort of sidelining your question—but one of the things is you see a cardiologist and they are an expert of the heart, or the ENT doctor who's an expert in the ear, nose and throat, and so I think on the surface that could be a little bit intimidating, but as a general internist I know that my breadth of knowledge and things I know that they don't, is significant because we practice different things. And I always make a joke of it to whoever it is, whether it's a GI doc or cardiologist, that when I do that part of the exam I always say; we are going to do a super-thorough cardiac exam today—as a joke, right?—to kind of break the ice that, you know—hey, I know you are a cardiologist and I'm a general internist. I'm going to do what I do, and it may not be up to your standards, so to speak, to sort of set the stage. And I think they are very respectful of the fact that they are experts in their field, but they have gaps in their knowledge and that is sort of why they come to see someone as a primary care physician (Interview 5E4).

I followed up to this physician's response, by noting the sarcasm he used in defending his own medical expertise. He responded to my comment by stating,

> I guess it's kind of a personality thing, I guess. I try not to treat any of the physicians differently than other patients, and so the thing I may do a little different is when we are discussing a medical problem that is in their area of expertise, I discuss it in the context of this is what I would recommend to you. If there is new literature or evidence that you're aware of that we need to have more dialogue of, my recommendation because of your area of expertise, let's have that dialogue. But I also do that for other patients and I'll say but let me know what concerns you have or what your knowledge of this is, so we know that your plan and my plan are the same so that it's actually going to get accomplished. And so it's just the way that I frame it for the physicians is—hey I know this is your area of expertise, this is what I would do for any other patient and if you have thoughts, questions, concerns or want to bring anything to my attention, let's put it on the table and discuss it (Interview 5E4).

Interestingly enough, with this response, we see a distinct difference in the role of the treating physician depending on who the patient is. With physician-patients, the treating doctor has less power in the decision-making, is concerned about whether he/she has made the right move, and engages in negotiations with the patient in order to provide the best care. However, for a non-medically educated patient, the power of

the treating physician remains largely unchallenged, and instead there is a bit of "This is my decision, if you have questions let me know" that comes from the treating physician, a more dismissive tone toward the average patient.

However, special treatment is not always the best treatment in terms of medical care, as it may subject physician-patients to more testing, and lead to a cycle of second guessing as to whether their care is being handled appropriately. Many of the interviewed physician-patients did not particularly expect or demand special treatment; however, in one case a physician-patient who had been receiving special treatment became upset when a different doctor ignored their medical education and insisted on treating the physician-patient perhaps as they would any non-physician patient. Of this a female physician-patient said,

> *One of the partners to my physician had stopped in and was like "Honey, have you and your doctor talked about this?" And I looked back at her and was like, "Honey, I'm a doctor" and yes we have. It was like one of those, know your audience. So I would say, I guess from that instance that I probably don't have a lot of tolerance for people who don't know their audience and are treating me like I don't know what the hell I'm talking about* (Interview 3A2).

In the above instance, it is important to recognize that even if special treatment is not expected by the physician-patient, there is a certain level of care they feel should be given. This interview also raises questions about the role of gender differences in medicine, and perhaps suggests that women in medicine feel a need to constantly prove themselves, and perhaps in a moment of vulnerability the female physician-patient felt an even greater need to defend her medical degree. Later on in the interview, the same physician stated about the above situation,

> *I mean, I was like ticked, because it was like years later and seriously almost insulting, kind of. I am able to take a step back and say yeah, I'm sure it's not plastered all over my chart that I'm a doctor but in some ways I was insulted that she would talk to anybody the way that she talked to me. I was like, sweetheart, seriously? Back off. So, yeah, I mean I think it is very easy to get, I don't want to*

> *say indignant, that is a little—probably not the best word—but to get upset and frustrated when you don't get better care especially when you give it to other people* (Interview 3A2).

What happens when physician-patients aren't heard? What happens when they feel they have received care that isn't what they needed? One female physician who was interviewed responded,

> *Well, the good news is, I have an M.D. So, I literally was thinking in my head, if he doesn't give me x medicines, I'll just call them in myself. So it was frustration and I did not feel heard which I think that's what led me to find a new doctor. I was like, boy, if you can't hear me say my illness is getting worse, despite all the appropriate therapies, really? I'm going to have to call in my own medicine?* (Interview 1H3).

The above comment the power struggles between physicians and physician-patients, and in some cases the inability of physicians to listen to the patients regardless of status. However, it also questions the differences that gender plays in the power roles between physician and patient. Here was a female physician, attempting to seek medical care from a male physician, who was ignoring symptoms and perhaps felt the patient was exaggerating her case. This also reflects the abilities of physicians to take control of their own care, a sign that if all else fails, they (physician-patients) can handle their care on their own. Perhaps it is interactions like the one above that push physicians to self-diagnosis and self-treat.

There were many examples throughout the interviews that suggested that physician-patients do in fact receive different care, and that they approach their illness, their appointments, and their physicians differently than typical patients. There were also many examples throughout the interviews that suggested that physicians have to consider their physician-patients differently when treating them, because they present illness differently.

What complexities do physicians face in treating a patient who is also a physician-patient? Physicians must recognize the effects (positive and negative) of blurring the boundaries between physician and patient when the patient is a physician, as many physician-patients are often friends or colleagues. Physicians must also recognize that a physician-patient may present their illness in a way that actively shapes or distorts their diagnosis, because of the patient's knowledge of illness scripts. Physicians must also be aware that their own self-doubt may cause them to run more tests on their physician-patients.

In contrast, what is it like to be the physician-patient? Of the interviewed physicians, many wish not to received special treatment, and want to be treated just like everybody else. Physician-patients are not afraid to challenge their physicians, and in some cases, take charge of their own care when their physicians are not listening to their needs. Physician-patients are empowered in their care, because they do not feel limited by what their physicians have or have not done in the time of the course of their treatment. While special treatment may not be expected, there is a level of respect that physician-patients demand from the physician and staff, a level of professional recognition that the physician-patient is not a typical patient. But it is also worth remembering that physicians do not ever treat just any patients, they are treating *people*. Physicians are people too.

There were many aspects of physician-patient relations that were beyond the scope of my study, or that could not be pursued in the time I had available. However, there are several questions I intend to pursue in the near future. What is it like to treat a physician's family? A

few interviewed physicians suggested that when their family receives care it is also different, as the family members have two physicians who are consulting on the case. Research on physician family experiences might help to further understand the gap between patients who have a medical education and those who do not, as well as the importance of having an advocate who is capable of providing medical advice. I would also like to further understand how gender, race, and socioeconomic status play into the care of patients, and specifically physician-patients. The scope of this research study remained strictly focused on themes in treating the physician and being the physician-patient. I am also interested in understanding how title, privilege and personal connectedness shape the medical experience, and even more so, the relationships between physicians and patients (including physician-patients).

In the midst of preparing my research thesis, I had the unfortunate need to encounter the medical system. As I had been deep in my analysis of interviews with physician-patients, I began to analyze my own experiences and compare it to those in the stories shared in the interviews.

I had just finished lunch, only to find myself clenching my stomach and racing to my bed in hopes to ease the nausea. The same thing had happened the previous week, and the week before that. Except now it was happening more and more as the weeks passed. Not a meal went by where I did not feel sick to my stomach. Was it all in my head? Maybe I was just stressed—after all, it was the last semester of senior year. Actually, it was probably my diet. I wasn't eating the best, opting for carry-out over homemade. Maybe I'm lactose intolerant, or

even gluten intolerant? I turned to the internet to solve my problems. What foods could I, should I eat? I figured I would try everything possible before calling my doctor; after all, I didn't want to be a bother if it was only stress-induced or perhaps if it was something I was making up—I was pretty quick to believe it was something horrible. I pushed my symptoms aside, just like the physician-patients. The only difference was my reasoning: the internet confirmed my own thoughts, whereas for the physician-patients it was their own medical education that decided their symptoms were worthy of seeing a physician.

After a few weeks of consistent agony, eating healthy, and exercise, my symptoms persisted and even got worse. I called to schedule an appointment. The first one in two years; much like the physician-patients, I thought that if I *felt* healthy, I *was* healthy, and there was no sense in wasting my physician's time for a physical. The receptionist answered.

"How can I help you?"

"I need to schedule an appointment to see Dr. K"

"What are coming in for?"

"Well, I know I haven't had a physical in over 2 years, so I definitely will need a physical, but I am mostly calling because I have been having some stomach issues that I would like to talk with her about."

"Is it something you need to be seen for right away?"

I thought for a second, I had been dealing with it for this long, what's another week?

"No, it isn't urgent, I don't need to see her today or tomorrow, but within the next week would be ideal."

"Okay, I'll send Dr. K a message and see how she wants me to schedule you. I'll call you back with an appointment time."

Later that afternoon, I received a call. I will be scheduled for a physical three months away. "Three months away?" I asked the receptionist. "There isn't anything sooner?" "No, unfortunately there is not." I hung up the phone. I was in tears at the thought of having nowhere to go, at this point I knew it was something more than diet, perhaps an ulcer, maybe a tumor, but probably an ulcer. I wasn't urgent enough…yet… to need the emergency room. I knew the urgent care wouldn't have much to say. Oh how I envied the physicians I had interviewed—how, with the dial of a button or a quick text, they were able to talk to their own physicians. I resented the thought that they were getting seen quickly by their physicians who were making extra time to see them. I was almost angered that I didn't have the same option. No. I had to wait, like the rest of us.

After two weeks of attempting to manage my symptoms, losing 20 pounds, surviving off of ginger ale and saltine crackers, and dealing with a new symptom of stabbing pain when eating anything, I called my physician's office again. I explained I had an appointment 3 months away, but I couldn't wait that long. They transferred me to a nurse, who upon hearing my symptoms merely suggested that perhaps it was heartburn. Heartburn? Really? No, this was no heartburn; this wasn't solved by Tums, or Pepto, or Prilosec; this was serious. I was offended by her idea that perhaps I was too stupid to know my own body. I thought of the physicians I had interviewed who were insulted when they, too, were questioned on their own knowledge. I waited again while the nurse, not I, sent a message to my doctor to explain my symptoms, to see if I really needed to come in as soon as I said I did.

Surprise! I got an appointment the next day. Yes, it was serious. After explaining my symptoms; having my stomach pushed on to test for abnormalities; and undergoing blood tests, ultrasounds, and an in-hospital nuclear medicine test, I was told I had gallbladder disease and that I would be referred to a surgeon. I spent my entire medical stay without telling anyone of my medical interest and my research on physician-patient relationships; I also did not tell my surgeon of coming from a family of physicians. I wanted to experience medicine as a patient and nothing else—just to see if it was different from the stories shared by the physicians I had interviewed.

I had made it all the way to the pre-op room, before the nurse anesthetist asked me about my allergies. The way I responded must have come across as being knowledgeable about medicine. She flat out asked me, “Do you work in the medical field? Because you sure sound like you know stuff.” I explained that I had experience in hospitals but did not have any formal training in medicine. She said, “You must have picked up on a lot of it then, because you sound like you have some medical education.” I found it comical, that in the effort to not “expose” myself and my fascination with the medical world, I had still managed to inform the hospital staff that I did, in fact, know some things. I can only imagine how difficult it must be for physician-patients to constantly be in those situations, of having to hold your ground on your medical knowledge.

As a non-physician patient, my experiences were similar, yet different from those of the physicians I interviewed. I was not able to challenge my doctor, although it was an option; I did not feel empowered enough or educated enough to suggest differently. I was not able to reach my doctor as easily; in fact, I hardly was able to consult my doctor throughout the entire case.

To this day, my care has not been handled by my primary care physician (PCP) but rather by her nurse practitioner, and then later my surgeon. Including follow-up appointments, I have had no direct contact with my physician. By contrast, most physician-patients were able to text, call, or email on personal accounts to receive medical advice and care. I was also forced to wait months to get in to see a doctor due to my own inabilities to accurately portray my symptoms as emergent. I was considered a passive patient, an example of the guidance-cooperation model. My age, gender, and education had allowed me to have some say in the care, but ultimately, my entire experience was guided by the physician. Even more so, when interacting with my surgeon, it was more likely considered to be activity-passivity model as I had no say in my surgical decisions, and was left without much detailed information as to how the surgery would be performed.

While I can't say I received any "special treatment," as most of the physicians I interviewed reportedly have had, I was still provided with excellent care. In fact, overall there are pros and cons to being both a physician-patient and a non-physician patient. I was not responsible for making my own health decisions as Paul Kalanithi felt he had to be. However, I also wasn't capable of challenging my physician's diagnosis and treatment because I lacked the medical knowledge and authority to do so. I, unfortunately, had to wait for the system in order to be seen, whereas physician-patients are often in direct contact with their physicians. These differences in no way diminished the care that either the physician-patients received or the care that I received—but for many who are unable to recognize the role of gender, status, age, and race in their medical care might feel differently. We are all people, we are all patients, including physicians. We all have a right to receive the care we need, to have physicians who

will listen to use regardless of our age, gender, race, status, and socioeconomic background and to have a say in our own care. We can all learn from physician-patients that it is okay to be empowered in your care, it is okay to challenge physicians—to dig deeper in to why and how they arrive at a diagnosis. We don't need medical degrees to be empowered in our own care, we just need the mind that would allow us to decide that we are important enough to do so. We need to educate and train physicians on the ways that not only knowledge, status, power and title can influence the care they both give and receive—but that it is not limited by gender, race, age and socioeconomic status.

References:

Davidson S.K., Schattner P.L. "Doctors' health-seeking behaviour: a questionnaire survey." *The Medical Journal of Australia,* 2003, pp. 302-305.

Domeyer-Klenske A., Rosenbaum M. "When Doctor Becomes Patient: Challenges and Strategies in Caring for Physician-Patients." *Family Medicine,* vol. 44, no. 7, 2012, pp. 471-477.

Donaldson, Liam J. "Sick Doctors." *The British Medical Journal,* vol. 309, 1994, pp. 557-558.

Fox F., Harris M., Taylor G., *et al*. "What happens when doctors are patients? Qualitative study of GPs." *British Journal of General Practice,* 2009, pp. 811-818.

Fromme, Erik, Billings, J. A. "Care of the Dying Doctor: On the Other End of the Stethoscope." *Journal of the American Medical Association,* vol. 290, no. 15, 2003.

Geha, R., Connor, D.M., Kohlwes, J., and Manesh, R. "Illness Scripts." *Journal of General Internal Medicine.* Website. 17 April 2016.

Kalanithi, Paul. *When Breath Becomes Air.* New York: Random House, 2016. Print.

Klitzman, Robert. "Improving Education on Doctor-Patient Relationships and Communication: Lessons from Doctors Who Become Patients." *Academic Medicine,* vol. 81, no. 5, 2006, pp. 447-453.

Markwell A.L., Wainer Z. "The health and wellbeing of junior doctors: insights from a national survey." *The Medical Journal of Australia,* 2009, pp. 441-444.

Sprio, H.M., Mandell, H. N. "On Being a Patient: When Doctors Get Sick." *Annals of Internal Medicine,* vol. 128, no. 2, 1998, pp. 152-154.

Waldron, H.A. "Sickness in the Medical Profession." *Annals of Occupational Hygiene,* vol. 40, no. 4, 1996, pp. 391-396.

Weiss, Gregory L., and Lynne E. Lonnquist. *The Sociology of Health, Healing, and Illness*. 8th ed., Routledge, 2016.